

# Infantile autism: impact of diagnosis and repercussions in family relationships

*Autismo infantil: impacto do diagnóstico e repercussões nas relações familiares*  
*Autismo infantil: el impacto del diagnóstico y efectos sobre las relaciones familiares*



Rayssa Naftaly Muniz Pinto<sup>a</sup>  
 Isolda Maria Barros Torquato<sup>b</sup>  
 Neusa Collet<sup>c</sup>  
 Altamira Pereira da Silva Reichert<sup>c</sup>  
 Vinicius Lino de Souza Neto<sup>d</sup>  
 Alyne Mendonça Saraiva<sup>b</sup>

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#### ABSTRACT

**Objective:** To analyse the context in which the diagnosis of autism is revealed and the impact of this revelation on family relationships.  
**Methods:** This is a qualitative study with 10 families of autistic children assisted at the Psychosocial Care Centre for Children and Youths in a municipality of Paraíba. Data were collected between July and August 2013 through semi-structured interviews and interpreted using thematic content analysis.  
**Results:** The identified Main Unit of Analysis and the respective categories were: the impact of disclosing the diagnosis of autism to the family; characteristics of diagnosis disclosure: the place, time, and the dialogic relationship between the professional and the family; changes in family relationships and the mother's burden when caring for the autistic child.  
**Conclusions:** The health professionals who report autism should better prepare the family to cope with the difficulties of this syndrome and autonomously care for the autistic child.  
**Keywords:** Autistic disorder. Diagnosis. Family relations.

#### RESUMO

**Objetivo:** Analisar o contexto da revelação do diagnóstico do autismo e o impacto deste nas relações familiares.  
**Métodos:** Trata-se de um estudo qualitativo, realizado com 10 familiares de crianças autistas, assistidas no Centro de Atenção Psicossocial Infância Juvenil em um município da Paraíba. A coleta ocorreu entre julho e agosto de 2013 por meio de entrevista semiestruturada cujos dados foram interpretados pela análise de conteúdo na modalidade temática.  
**Resultados:** Identificou-se uma Unidade Temática Central com respectivas categorias: o impacto da revelação do diagnóstico de autismo para a família; características da revelação do diagnóstico: o local, o tempo e a relação dialógica entre o profissional e a família; alteração nas relações familiares e a sobrecarga materna no cuidado à criança autista.  
**Conclusões:** Há necessidade do profissional de saúde que noticiará o autismo saber preparar melhor a família para enfrentar as dificuldades impostas pela síndrome e para conquistar a autonomia no cuidado ao autista.  
**Palavras-chave:** Transtorno autístico. Diagnóstico. Relações familiares.

#### RESUMEN

**Objetivo:** Analizar contexto de revelación del diagnóstico de autismo y el impacto de esto en las relaciones familiares.  
**Métodos:** Se trata de un estudio cualitativo con 10 familiares de niños autistas que reciben asistencia en el Centro de Atención Psicossocial para Niños y Jóvenes en un municipio de Paraíba. Los datos fueron recolectados entre julio y agosto de 2013 a través de entrevistas semiestructuradas y los datos fueron interpretados por el análisis de contenido en la modalidad temática.  
**Resultados:** Se identificó una Unidad Temática Central con respectivas categorías: el impacto de revelar el diagnóstico de autismo para la familia; la divulgación de las características de diagnóstico: el lugar, la hora y la relación dialógica entre el profesional y la familia; cambios en las relaciones familiares y la sobrecarga ,manterna en el cuidado del niño autista.  
**Conclusiones:** Existe la necesidad de profesionales de salud que informarán el el autismo para preparar mejor a la familia para hacer frente a las dificultades impuestas por el síndrome y para la autonomía en el cuidado del autista.  
**Palabras clave:** Transtorno autístico. Diagnóstico. Relaciones familiares.

<sup>a</sup> Universidade Federal de Campina Grande (UFCG), Hospital Universitário Alcides Carneiro, Campina Grande, Paraíba, Brasil.

<sup>b</sup> Universidade Federal de Campina Grande (UFCG), Curso de Enfermagem, Campina Grande, Paraíba, Brasil.

<sup>c</sup> Universidade Federal da Paraíba (UFPB), Curso de Pós-graduação em Enfermagem, Curso de Graduação em Enfermagem, João Pessoa, Paraíba, Brasil.

<sup>d</sup> Universidade Federal do Rio Grande do Norte (UFRN), Programa de Pós-Graduação em Enfermagem, Natal, Rio Grande do Norte, Brasil.

## ■ INTRODUCTION

Autism, also known as Autistic Spectrum Disorder (ASD), is defined as a behavioural syndrome that affects motor and neuropsychological development and impairs social interaction, cognition, and communication in children<sup>(1)</sup>.

Its aetiology remains unknown, however, it is currently considered a syndrome of multicausal origin that involves genetic, neurological, and social factors of children<sup>(2)</sup>. Today, there are an estimated 70 cases of ASD for every 10,000 inhabitants worldwide, and it is four times more common in boys<sup>(2)</sup>. In Brazil, despite the paucity of epidemiological studies that could provide a national estimate, a recent survey found that there are 27.2 cases of autism for every 10,000 inhabitants<sup>(3)</sup>.

The possible reasons for the increase in cases of this syndrome include changes in diagnostic criteria, increased awareness of parents and society about cases and clinical manifestations, and the creation of specialised services for ASD<sup>(2)</sup>.

Recognition of the symptoms manifested by the child with autism is critical for early diagnosis. The clinical manifestations are usually identified by the parents, caregivers, and family members who notice characteristic behaviour patterns of autism in the child<sup>(4)</sup>.

The signs have varying levels of expressiveness and generally start before three years of age. Children with ASD exhibit a unique triad that is characterised by qualitative difficulties and losses of verbal and non-verbal communication and social interactivity, and a restricted cycle of activities and interests. The symptomatology of this type of disorder can also include stereotyped movements and mannerisms, a variable pattern of intelligence, and an extremely labile temperament<sup>(5)</sup>.

This situation triggers changes in family life since the development needs of the child must be closely monitored. The diagnosis of chronic illness in the family, especially when it involves children, causes an impact because the family must change its daily routine and readjust roles, which affects work, income, and inter-family relations. When the family is confronted with the diagnosis of a chronic illness or syndrome, as in the case of ASD, it usually goes through a sequence of stages, namely: impact, denial, grief, external focus, and closure, which are associated with difficult and conflicting feelings<sup>(6)</sup>.

Thus, it is understandable that the disclosure of a diagnosis of autism is considered a complex, delicate, and

challenging moment for the families and for the health professionals responsible for this mission. The physical environment associated with the other circumstances of this disclosure may or may not mitigate the family's suffering.

Lack of time, the inability to communicate, and the absence of emotional support of health professionals are still barriers to appropriate disclosure, which legally pertains to the doctor. However, the presence of a multidisciplinary team in this process is important because the members involved can share their questions and anguish, and acknowledge the needs of the family at the moment of disclosing the diagnosis.

It is also important to plan how the family will be notified of the diagnosis while maintaining an open and understanding dialogue to facilitate the flow of provided information, and create coping strategies that can help the family accept the diagnosis.

In order to better understand the specificities of the dialogical relationship between health professionals and the families at the time of diagnosis of autism and the impact of this diagnosis on family relationships, the authors created the following questions: How does the disclosure of a diagnosis of autism affect the family? How is the diagnosis disclosed? What are the repercussions of the diagnosis of autism in family relations?

This study is justified by the scientific relevance of the topic and the possible contributions that it will provide health professionals and academics with regard to understanding the dialogical relationship between the health professional and the family confronted with a diagnosis of child autism, and its impact on family relationships. The aim of this paper was to analyse the context in which a diagnosis of autism is revealed and the impact of this revelation on family relationships.

## ■ METHODS

This a descriptive, exploratory study with a qualitative approach conducted at a benchmark Psychosocial Care Centre for Children and Youths (CAPSI) of a municipality of Paraíba, Brazil, that specialises in assisting children with autistic disorder.

The population consisted of the family members who accompanied the autistic children to the service. The criteria for inclusion for participant selection were family members of children diagnosed with autistic disorder confirmed with the presentation of a medical report with ICD (International Classification of Diseases), and family members who

lived with the child. The criterion for exclusion was family members of children with some kind of mental disorder or communication impairment.

Based on these criteria, the sample consisted of 10 families. It should be noted that sample composition observed the premises of the qualitative tradition, in which no relevance is given to the statistical representativeness of the sample in the sense of generalising the findings, but to subjective accumulation regarding the object that is being unveiled, which is known as a theoretical sample<sup>(7)</sup>.

Data were collected from July to August 2013. For the interviews, the coordination department of the sector was contacted in advance to ensure the feasibility of research. The researchers directly approached the family members immediately after the children's consultation with the healthcare professional to explain the objective of the research and its relevance regarding assistance for children with autism. The length of the interviews observed the work shifts of the unit and occurred from 8:00 a.m. to 12:00 p.m. and from 1:00 p.m. to 5:00 p.m.

The semi-structured interviews were divided into two parts; the first sought to characterise the participants by age group, marital status, education, and income, while the second contained questions inherent with the study. These questions were: How did your family react to the diagnosis of autism? Where was the diagnosis disclosed? Who disclosed the diagnosis? Talk to me about this moment. What were the repercussions of the diagnosis of autism in your family relations?

The interpretation of empirical data observed the stages recommended by the thematic content analysis technique, namely: data encryption; data categorisation; and interaction of thematic nuclei. The analysis began with reading and re-reading the interviews to identify the focus of concern or difficulty of the families, and the acquired skills. Thus, it was possible to identify the categories and integrate them into a thematic nucleus<sup>(7)</sup>.

In the presentation of results, the letter "E" (Interviewee) was used, followed by an Arabic numeral to identify the child's family member. Since this investigation involved human beings, the research project was submitted to the research ethics committee of the Alcides Castro University Hospital (HUAC) and approved under CAAE #16216013.2.000.5182, as required by Resolution 466/12 of the national health council (CNS).

In order to meet the ethical principles stated above, the participants involved in the research were informed of the

goals of this survey, and subsequently signed two copies of an informed consent statement, one of which remained with them and the other remained with the researcher responsible for the study.

## ■ RESULTS AND DISCUSSION

The participants were 25 to 56 years old. All the participants were women, in a stable marital relationship (90%), who had finished secondary school (70%), and had an income of up to one minimum wage (80%). The statements were used to define the Main Unit of Analysis titled, "Revelation of the diagnosis of autism in children and the repercussions in family relationships", which, in turn, led to the emergence of three categories of groups of perception of the participants that allowed more room for discussion and helped guide the study. These categories are:

### Category I: The impact of disclosing the diagnosis of autism to the family

The diagnosis of a chronic disease or syndrome in a family triggers a set of emotions and feelings such as frustration, insecurity, guilt, grief, fear, and hopelessness, especially when the patient is a child<sup>(8)</sup>. The birth of a child represents the start of a new life cycle that is idealised by the parents and the whole family. When these plans are ruptured in any way, it affects all the family members<sup>(6)</sup>.

For the interviewed family members, the diagnosis was perceived as stressful and life-changing since the idea of having a child that is outside the concept of normality has major repercussions in the family context. At first, the ambiguous feelings of the family members regarding the discovery of autistic spectrum disorder in the child ranged from sadness and grief to denial.

*I felt really insecure, you know? Like any mother, I suffered a lot when I was told that she had this problem ... didn't want to believe it. I realised she was different, but you never want to believe that the child has something, a disease [...] whatever [...]. When he (the doctor) told me what she had, I did not want to accept it at first. I was very sad. (E3)*

*For me it was like a shock, you know? But I had to accept it. I was very sad at first. (E4)*

*I didn't believe it myself [...] people would say: "This boy is different". They told me to take him to the doctor [...].*

*When the doctor told me, my first reaction was to not believe him (E5).*

*In my mind, I could not accept he was autistic. I denied it at first, but then I accepted it. (E6)*

The statements of the family members reveal how hard it was for them to hear their child had autism. Most of the interviewees used denial as an escape strategy, despite the confirmation of diagnosis.

According to authors<sup>(9)</sup>, the impact of a diagnosis of a disease can trigger the same stages of mourning or grief as those felt by people who have lost something highly desired or significant. Feelings of guilt are also common among family members, specifically the parents. However, the statements of these subjects did not reveal guilt in relation to the diagnosis of ASD in the child.

The feelings experienced by the family members at the moment of the diagnosis may be more intense due to their ignorance of this disorder, and considering that they may perceive the diagnosis as a definitive loss of the child, as shown below:

*At the time we didn't know what autism was [...] and that made us even sadder and more worried because we didn't know what autism was. (E2)*

*[...] I was shocked at the time because I didn't understand what autism was. At first, it was very difficult because I thought it was something very serious. I didn't ask anything else [...] I was lost and he said I only had to treat it, but didn't say how. (E3)*

*When the doctor said: "Your son has autism", that was it, I thought the worst. I didn't know what it was and it made me even more desperate at the time because I didn't know what I was dealing with. Not knowing made it worse still when I got the news because I didn't know what it was [...] Maybe if I had known it wouldn't have been so bad. (E6)*

These statements show the importance of expanding the scope of information beyond the name of the pathology since a disease can only be accepted when there is enough information of the disease and ways to treat it, and by perspectives of prognosis<sup>(10)</sup>.

The family members of this study revealed that they felt they did not receive enough information about ASD and its prognosis. Although treatment was mentioned in

most of the statements, the way treatment is approached is non-specific since no clarifications are given regarding the time, place, and how it will occur. Furthermore, some interviewees did not feel free to ask questions about the prognosis of autism in the child, and they left the consultation room without understanding what the syndrome is really about.

According to authors<sup>(11)</sup> establishing a link between the patient-family and the healthcare professional is very important at the moment of revealing the diagnosis since the quality of the information can reflect positively on how family members face the problem, and encourage them to ask questions and participate in decision-making regarding how to treat the problems they experience.

It is of the utmost importance that they understand the causes of autism and, above all, the consequences that arise from autism. Positive or negative expectations of the development and future of the child can be influenced by how they understand the information and resources they are offered for the child's proper development<sup>(6)</sup>.

Another aspect that affects and compromises the family's acceptance of the disease is the delayed conclusion of the clinical diagnosis. Until the family members receive a definitive diagnosis, they continue to hope that the child's problem is simpler than expected and create false expectations that the signs and symptoms are transitory and solvable despite clinical evidence of the disease.

*I didn't know that this girl was like that, you know? [...] I realised she had some difficulties, like mumbling "hum hum", and I only found out she had autism when she was 5 years old. That delay distressed me, you know? Because deep down I hoped it was nothing and it was hard to accept. (E1)*

*My mother didn't want to believe it much, but when she (sister) was small, she had lots of compulsive habits [...] and the delayed diagnosis only made my mother believe that it was nothing serious. (E2)*

*My grandmother was the first to notice. He was very agitated. She said things like: "This boy has a problem" [...] and I was the only one who wouldn't accept it. It took them ages to give me the diagnosis and it just made me hope that he had nothing. (E6)*

*They only discovered the diagnosis when he was 6 years old [...] I was sad because I had hoped it wasn't a*

*big deal. Like this! The delay made it hurt more when I found out. (E7)*

Some of the possible causes of delays in the diagnosis of autism include the absence of specific examinations for the syndrome and the fact that the diagnosis is based on the child's history. Another issue is the variability of the symptoms and the absence of specific training for health workers to deal with the disorder. According to authors<sup>(12)</sup>, the early diagnosis and treatment of paediatric disorders are essential for the child's clinical evolution since it enables the achievement of positive physical, mental, and social results.

The denial of family members that the child has a pathological alteration can be triggered by fear of the unknown and social isolation and rejection, whereas the stigma and segregation suffered by the child have unpleasant effects, especially when they are experienced within the family. <sup>6</sup>Most of the participants were the mother of the child. The fear of the reaction of other relatives, especially the father's family, had a profound effect on these mothers during the diagnosis. The interviewees emphasised that, at the moment of diagnosis, they feared that the parental grandparents and uncles or aunts would discriminate the child.

*[...] Like any mother, I suffered a lot when he was a minor [silence] the father's family? I was afraid they wouldn't like her. (E3)*

*I didn't want to accept for fear of prejudice from others and the neighbours [...] (E6).*

*I was afraid she would be rejected by people. I didn't know how it was going to be. At the time I didn't accept it because of several reasons, but I thought a lot about the prejudice of people and my husband's family. (E8)*

*[...] I was afraid that my husband's family when they found out they would treat her differently to the others [...]. (E9)*

It is a lot harder for the parents, especially the mothers, to experience these differences. For them, realising that people feel uncomfortable with the presence of the autistic child is an act of prejudice. Furthermore, any offence directed toward the child is considered an offence directed toward them. The perceived prejudice and discrimination often makes them overprotective of the child as if he or she were a fragile and helpless being<sup>(13)</sup>.

Although this syndrome is still incurable, it is important to note that an early diagnosis can lead to evolutions in the behaviour, motor skills, interpersonal interaction, and communication skills of the child. However, it is important that parents encourage the child by overcoming the prejudiced views and inserting the child in society<sup>(12)</sup>.

### **Category II: Characteristics of diagnosis disclosure: the place, time and the dialogic relationship between the professional and the family**

The context in which a diagnosis of a chronic disease is revealed can directly influence how it is accepted or denied, although in the latter case the effects lead to a much more profound impact, as well as sadness and anguish. Some aspects should be taken into consideration at the time of diagnosis, and one of these aspects refers to the choice of a physical environment. The setting must be tranquil, comfortable and private<sup>(14)</sup>.

In all the cases investigated in this study, it was found that the diagnosis was given at outpatient consultation rooms by medical professionals. However, although this setting is the most widely mentioned in literature to disclose a diagnosis, there are still situations in which the patient and the family receive the diagnosis through letters, phone calls, in wards, and in the hallways of hospitals.

*They gave me the diagnosis here at the CAPS in the doctor's office. It was me and the doctor. (E1)*

*The diagnosis it was the doctor of the APAE who discovered it. He said that the child had autism. We went there for an appointment and he told us. It was my mum and me in the office. (E20)*

*The diagnosis was given to us at the APAE in the doctor's office, then they referred me to the CAPS and they confirmed it. It was just us. (E4)*

The news of a diagnosis, depending on the disease, is understandably devastating for the family of the patient. Therefore, the manner and setting in which it is given must involve intense approximation and interaction between the doctor, the other health professionals, the patient, and the family. Moreover, the absence of an appropriate setting for the diagnosis can compromise a dialogic relationship between the health worker and the receivers of this diagnosis, and prevent the latter from feeling at ease to externalise their feelings and

request explanations about the disease and treatment they must follow.

Regarding the manner of communication, this is considered one of the main aspects of care, especially when revealing a diagnosis to the family members of a child with a chronic syndrome or disease. It is, therefore, important for health workers to understand the particularities and characteristics of every individual, and consider their experience and familiarity with technical and scientific terminology.

According to the family members, the communication at the moment of the diagnosis was quick, direct and cold, without elaboration or prior preparation with information about autism. In other words, for the chaperones, the manner in which the diagnosis was disclosed was superficial and incomplete, without any in-depth information from the health worker regarding the disease and its particularities, as noted in the statements below:

*[...] The doctor said "this child has autism" and did not explain much. (E2)*

*[...] The doctor turned and said in our face, "This child is autistic". (E3)*

*[...] The doctor just said to me "Mum your son doesn't have autistic traits, he is actually autistic." He didn't prepare me and was very direct. (E4)*

In some situations, the discovery of an illness on the part of health professionals is a purely mechanical situation without concern for the feelings or reaction of the patients or their families. According to authors<sup>(14)</sup>, the news should be communicated in a clear, honest, respectful, comprehensible manner that considers the social and cultural characteristics of the patients and their families. It should also exclude jargon since the perceptibility of the message and the understanding of the message are closely related to how the professional conveys the information.

However, research<sup>(10)</sup> shows that a significant percentage of the doctors are still unable to establish a dialogical relationship with patients and their families about the disease/syndrome. Ambivalent messages and the omission of information are also common, especially among non-specialists. The difficulty of transmitting information on the part of the doctor may be justified by cultural, social, and emotional differences that somehow force doctors and other healthcare professionals to exercise their activities in a patient-centered and less paternalistic manner<sup>(15)</sup>.

The lack of consideration regarding the manner in which a diagnosis is communicated, which is an important aspect of care, will evidently cause tension and emotional conflicts on the part of patients and their families.

Another problem addressed in literature that may or may not facilitate the disclosure of a diagnosis is the short time available for each consultation, which hinders the establishment of a closer relationship between the doctor and the family and consequently prevents doctors from meeting the family's demands<sup>(16)</sup>.

Doctors must usually attend a high number of patients in a short period, which can prevent them from correctly preparing and filtering the information they must convey to patients and their families. This issue was mentioned by the family members interviewed in this study. They also considered that the short period available to disclose the diagnosis caused some disappointment because they were unable to listen and be heard, which is needed for the health professionals and the family members to establish some form of bond.

*[...] He only said that the child had autism. It was quick. He didn't say anything else [...] and that's when I asked: "Yes doctor and what is that? Is it serious? Explain it to me better. What do I do? Is there treatment? It was something like that". (E2)*

*[...] The doctor turned and said up front, "This child is autistic". That was it. He didn't talk about it. He just referred me to get treatment for her. I couldn't ask him anything because he immediately referred me to another sector. (E3)*

*[...] The appointments were quick. It was only here at the APAE that the doctor told me the diagnosis during the appointment. He just said the diagnosis quickly and referred me to the CAPS. That was it. That's when he started treatment. (E4)*

### **Category III: Changes in family relationships and the mother's burden when caring for the autistic child**

The diagnosis of a disability in a child brings about a new reality for the family, especially among the parents. An illness or disability can be a stressor that affects the routine and relationships of the family members.

It is only after the unexpected diagnosis of a syndrome/chronic illness that the family starts to endure and

make continuous adaptations to meet the needs of the child. The initial impact can be so intense that it affects the marital relationship between the parents and how the family members accept the child, and the family may need a long adaptation period to regain the balance and start the coping process<sup>(6)</sup>.

The adaptations and negotiations of new roles are easier when the family accepts the child and begins to participate in the process of care, as revealed in the statements. For the respondents, the way the other members of the family treat the child – siblings, grandparents, uncles, aunts and cousins – is important if they are to overcome the diagnosis and cope with the daily adaptations.

The statements also reveal that acceptance of the child by the family minimises the impact of the diagnosis and helps make family relationships more solid, especially among parents and siblings. However, it should be noted that some of the participants reported that members of the family distanced themselves because of prejudice, especially the paternal family, which ruptured emotional ties and caused sadness and disappointment.

*[...] The relatives of her father are estranged. They do not visit her. They are distant. They drifted away after the diagnosis was confirmed. (E3)*

*[...] He only sees my family. The paternal relatives are distant; it seems that they do not understand [...] he has more contact with the people from my family, with my nieces only that with his father's family he has no contact. (E5)*

*[...] My family had no prejudice. They supported me. On the father's side, there is no contact. Some refuse, like grandmother and grandfather, to be with him. They don't come visit my son, you know? I can say that there is no affection from them. The affection is different, the love is different. (E6)*

The way the child is treated by the relatives and the changes inherent in the syndrome, such as commitment to communication, in the pattern of social relations and behaviour, causes the parents to naturally seek special care for the autistic child. The resulting overprotection causes conflict and jealousy among the other siblings and can often affect the emotional relationships among all the family members. The jealousy of the other siblings is justifiable since they can feel less loved and appreciated because of their sick brother or sister<sup>(17)</sup>.

However, despite the jealousy mentioned by the siblings in most of the literature on this subject, in this study, the siblings unanimously externalised more concern, patience, and love toward the child with autism, which made their relationship closer and more fraternal, as mentioned in the statements.

*[...] The relationship with his siblings is very good. They like him very much. They sleep with him, there is affection. It has always been like that. (E7)*

*[...] In my house, everyone is close. Thank God my kids get along fine. I never had problems with them. We combine. (E1)*

*[...] I have a 9-year-old girl, too. She really cares about her brother. She loves him and treats him very well and with care [...]. (E4)*

With regard to sharing the task of caring for the child, it was observed that, despite the need to adapt the family roles and mobilise the family to share the activities, most of the care is provided by the mother or mother figure, especially when the father is not an active parent. The fathers usually claim that they do not fully participate in the overall care of the child because of their financial and work responsibilities regarding the family.

The burden of the mother who cares for a child with chronic disease is based on a historical and cultural construct since society assigns the role of primary caregiver to the female figure. Emotional ties can also justify the protagonism of mothers as caregivers. The mother's statements revealed that caring for the autistic child is a priority in their daily lives. They devote their entire day to caring for the child, which means they cannot work outside the home or engage in another activity.

*[...] I take care of her because the boys go to school and her father works in the country [...]. (E1)*

*[...] I take care of him. I get him up, bathe him, feed him, put him to sleep, get him ready and watch over him [...] the father works in the grocery store all day. (E5)*

*[...] She spends the entire day with me. I take care of her day and night. The father helps when he comes home from work at night, but I am the one who really does everything because he's at work all day and I stay at home taking care of her. (E8)*

In this study, the respondents mentioned that some family members helped with the tasks. However, the

statements refer to specific actions that the mother requested because she had other duties or household chores to do. The family members who were more frequently available to help take care of the autistic child were the maternal grandparents and siblings. The caregivers mentioned the fathers regarding the livelihood of the child and stated they seldom shared the daily tasks since they all worked out of the home and could only help on specific days or times.

*[...] Just my grandmother and grandfather watch him. When I go out to do something, they bathe him and put him to bed. Only when I left him with them. (E6)*

*[...] I am the one who takes care of him, but when I need help, when I can't give him a bath, his brother does it. The younger sister gives him a bath. (E8)*

*[...] Sometimes I leave him at my mother's house or with his father. Usually, when I need to do something outside the house, I am the one who mostly takes care of him [...]. (E9)*

The extended family members like uncles and cousins often have restrictions regarding accepting and relating to the autistic child, which prevents them from helping the primary caregiver with the child's care. In some statements, we also identified the stigma and difficulty in helping to care for the child because he or she is considered fragile and of difficult interaction.

It should be stressed that the full-time dedication and centralisation of the care provided by the mother, who also needs to renounce a professional career and divide her attention with other children, spouse and domestic tasks, can have significant physical and mental repercussions.

Joint pain, such as cervical and back pain, insomnia, anxiety, fatigue, and depression are some of the most commonly mentioned complaints of the primary caregivers. However, in the case of the caregivers of autistic children, the heaviest burden is the emotional strain, and the cognitive impairment of the autistic child was considered the main cause of stress by the primary caregivers<sup>(18)</sup>.

## ■ CONCLUSIONS

The results of this work shed valuable light on the repercussions of a diagnosis of Autism Spectrum Disorder (ASD) in the family context, especially in relation to family relationships. The expectation of the idealised child is frustrated and the diagnosis is initially difficult to accept,

especially by the paternal family members, who generally distanced themselves from the child.

The parents often find it difficult to accept the diagnosis because they lack information on the syndrome, which reinforces the importance of greater support, care, and guidelines from the healthcare professional who will notify the family of the diagnosis of autism. Although the diagnosis was given in a suitable setting, the family members stated that the manner in which the diagnosis was notified was objective and cold, which only made this moment harder for the direct recipients.

It is, therefore, important that health professionals provide all the necessary information and answer any questions and queries of the family members, and that health workers, including nurses, adopt strategies that help the family accept the diagnosis. The limitation was that this study was conducted in a specific geographic area in northeastern Brazil.

However, this study can help nurses better direct their knowledge regarding the particularities of autism and its repercussions on the family, and provide insight into the practice, teaching, research, and management of new healthcare intervention and action strategies, such as the construction of educational nuclei.

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■ **Corresponding author:**

Vinicius Lino de Souza Neto  
E-mail: vinolino@hotmail.com

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